



September 8, 2023

The Honorable Debbie Wasserman Schultz
U.S. House Of Representatives
270 Cannon Office Building
Washington, DC 20515

The Honorable Brian Fitzpatrick
U.S. House Of Representatives
271 Cannon House Office Building
Washington, DC 20515

The Honorable Mark DeSaulnier
U.S. House Of Representatives
503 Cannon House Office Building
Washington, DC 20515

The Honorable Amy Klobuchar
U.S. Senate
425 Dirksen Senate Building
Washington, DC 20510

The Honorable Ben Cardin
U.S. Senate
509 Hart Senate Building
Washington, DC 20510

Dear Representative Wasserman Schultz, Representative Fitzpatrick, Representative DeSaulnier, Senator Klobuchar, and Senator Cardin:

The undersigned childhood cancer organizations are members of the Alliance for Childhood Cancer, consisting of patient advocacy groups, healthcare professionals and scientific organizations, representing Americans who care deeply about childhood cancer. We are writing to offer our endorsement of H.R. 4363/S. 2213, the Comprehensive Cancer Survivorship Act. Thank you for your leadership in the fight against childhood cancer.

Each year in the U.S., an estimated 16,000 children are diagnosed with cancer. Approximately 1 in 263 children in the U.S. are diagnosed with cancer before their 20th birthday. Unfortunately, 1 in 5 children diagnosed with cancer in the U.S. will not survive, and for the ones who do, the battle is never over. By the age of 50, more than 99% of survivors have had a chronic health problem, and 96% have experienced a severe or life-threatening condition caused by the toxicity of the treatment that initially saved their life, including brain damage, loss of hearing and sight, heart disease, secondary cancers, learning disabilities, infertility and more.

While nearly 500,000 survivors of childhood and adolescent cancer are alive in the U.S. today, children do not have adequate access to a complete and coordinated survivorship care system. With survival rates for those diagnosed with childhood cancer increasing annually, childhood cancer survivors are often unprepared as they leave treatment and transition back into primary care. Further, there exists a significant gap in provider knowledge of childhood cancer survivorship guidelines and the important additional care needs and late effects of treatment.



The Comprehensive Cancer Survivorship Act aims to address the entire continuum of care for the estimated 1 in 900 people in the U.S. that are childhood cancer survivors. This legislation also addresses important issues discovered by the Government Accountability Office in their 2020 report, “Survivors of Cancer: Factors Affecting Access to Follow-up Care,” including cancer care and survivorship care planning, employment barriers for survivors and caregivers, and fertility preservation.

Thank you for your leadership on behalf of children with cancer. We look forward to working with you to enact the Comprehensive Cancer Survivorship Act. Should you have any questions or need additional information, please contact Sarah Milberg, Co-Chair of the Alliance for Childhood Cancer, at smilberg@allianceforchildhoodcancer.org, or Dr. Michael Link, Co-Chair of the Alliance for Childhood Cancer, at mink@stanford.edu.

Sincerely,

The Alliance for Childhood Cancer

American Academy of Pediatrics

American Cancer Society Cancer Action Network

American Society of Pediatric Hematology/Oncology

Andrew McDonough B+ Foundation

Association for Clinical Oncology

Association of Pediatric Hematology/Oncology Nurses

Association of Pediatric Oncology Social Workers

Children's Brain Tumor Foundation

Children's Cancer Cause

Leukemia & Lymphoma Society

National Brain Tumor Society

Pediatric Brain Tumor Foundation

Rally Foundation for Childhood Cancer Research

St. Baldrick's Foundation